

**Middle-Aged and Older People with AIDS: Trends in  
National Surveillance Rates, Transmission Routes,  
and Risk Factors**

Marcia G. Ory, Ph.D., M.P.H. and Karin A. Mack, Ph.D.

To Appear in Special Supplement to Research on Aging

November 1998

Address Correspondence to:

Marcia G. Ory, Ph.D., M.P.H.  
Behavioral and Social Research Program  
National Institute on Aging  
Gateway Building, Suite 533  
Bethesda, MD, 20892-9205  
Phone: 301-402-4156  
Fax: 301-402-0051  
EMAIL: Marcia\_Ory@Nih.Gov

## **ABSTRACT**

Although the concerns of middle-aged and older people as infected with or affected by HIV/AIDS have received scant research or program attention since the beginning of the AIDS epidemic, national data is emerging to show how older people are both similar and different from younger populations. This paper explores the stability and changes in national trends related to AIDS rates, transmission routes and risk factors from the mid 1980s to 1997. We show that while the numbers of AIDS cases have grown dramatically for all age groups, the proportion of cases for persons 50 years and older (at diagnosis) has remained a fairly stable ten percent of the total case load, resulting in over 60,000 cases in 1997. Contrary to popular belief, the most prevalent transmission route for middle-aged and older people has always been through sexual contact. While middle-aged and older people may be at reduced risk compared to younger age groups, these data also reveal a disturbing trend. People 50 years and older continue to be less knowledgeable about AIDS risks, perceive themselves to be at lower risk, and for those with known AIDS-related risks, have made fewer behavioral accommodations to avoid such risks as compared to younger people. With recent data indicating a faster rise in new AIDS cases among the 50 plus population, middle-aged and older people can no longer be ignored in AIDS prevention or treatment efforts.

The concerns of middle-aged and older people as infected with or affected by HIV/AIDS have received scant research, programmatic, or policy attention since the beginning of the AIDS epidemic. This is despite the fact that in the United States, to date, there have actually been more cases of AIDS in the geriatric population than in young children. According to national surveillance data (CDC, 1997), the cumulative case AIDS caseload as of 1997 reported 8,530 cases in adults 65 and older and 6,343 cases in children five and younger.

The now classic volume on AIDS in an Aging Society (Riley, Ory, and Zablotsky, 1989) first drew attention to the myriad ways older people could be involved in the epidemic and identified research and practice needs. While the numbers of cases in the older population was relatively modest in the 1980s, the consequences of HIV/AIDS for middle-aged and older people were actually much larger than the small number of cases suggested. Understanding the influence of AIDS in a aging society requires attention to older people at risk for HIV/AIDS, those living and dying with HIV/AIDS, those caring for family members and friends, or those providing professional care for people with

HIV/AIDS. Building on the recommendations from the first AIDS and Aging Conference held in 1987, for the past decade, the National Institute on Aging has spurred research efforts to examine the role of aging factors in the HIV/AIDS epidemic (NIA, 1997). The Year 2000 National Research Plan for AIDS Research, coordinated through the NIH Office of AIDS Research, (NIH, 1998) has included attention to life-course and aging issues in both basic and intervention research objectives and strategies. While HIV/AIDS behavioral research with aging populations is just emerging, epidemiological studies report that older people are diagnosed later, that survival is shorter, and that prevention programs are generally lacking for the 50 plus population (AARP, 1994; Adler and Nagle, 1994; Gluck and Rosenthal, 1996; Ferro and Alit, 1992; Keitz et.al, 1996; Nokes, 1995; Skiest, Rubinstein, Carley, Gioiella, and Lyons, 1996; UCSF, 1997; Whipple and Scura, 1996).

Prevention efforts in the 50 plus population are hindered by a lack of public awareness of the AIDS rates, transmission routes, and risk factors in this population. Drawing on CDC surveillance data, this paper will document the stability and changes in the numbers of persons with AIDS and routes of transmission. Comparisons will be made between the younger and older population, as well within

the older population itself. It must be noted that this CDC data is based on age at diagnosis of AIDS not age at the time of infection. Gender and ethnicity differences are also present, but these will not be highlighted since they will be explored in greater depth in other chapters in this Volume (see Brown and Sankar, 1998, and Zablotsky, 1998.) Other data will be cited briefly to assess older people's relative knowledge of AIDS risks as well as self reports on behaviors to reduce AIDS-related risks (see Strombeck, 1998 for a fuller presentation of these issues). While the majority of data presented will be prevalence rates, new CDC data on AIDS rates in 1997 will also be highlighted to indicate the increased vulnerability for the older population if prevention programs directed toward older people and their health care providers are not initiated.

### *The AIDS Caseload*

The numbers of AIDS cases in the United States have increased dramatically since the beginning of the epidemic. In absolute terms, the cumulative numbers of reported persons with AIDS has increased from 41,906 in 1986 to 641,086 Americans in 1997. As of December, 1997, there were over 60,000 people diagnosed at aged 50 and older with AIDS since the beginning of the epidemic (see Table 1). The

bulk of cases fall in the younger age ranges of the 50 plus population, yet, 8,530 cases were diagnosed in persons 65 years and older.

The gender and ethnicity distribution of AIDS cases in the 50 years and older group is similar to that of younger populations. The majority of the AIDS cases in the 50 years and older group are men (84%), and cases also overrepresented minority populations (e.g., African-Americans and Hispanics account for almost 60% of all reported AIDS cases in this population)(CDC, 1998). Differences do emerge for the oldest AIDS cases in that they are more likely to be male and less likely to be Hispanic than younger cases (CDC, 1998).

While there has been rapid change in absolute numbers, the percentage of AIDS cases diagnosed at 50 and older has remained remarkably stable. From 1982 to 1997, the 50 plus population has accounted for 10% of the cumulative AIDS caseload.

This ten percent figure which is widely quoted is actually a slight undercount of the impact of AIDS in the middle-aged and older population if one examines the actual age of persons living with AIDS. Table 2 takes the 573,751

AIDS cases reported cumulative to year-end 1996<sup>1</sup>, deletes those who are no longer alive and adjusts the numbers to reflect an estimate of actual age, rather than age at diagnosis which is generally reported. The table shows that nearly 15% of the AIDS caseload is 50 and older.

While CDC reported the first ever decline in numbers of adult diagnosed with AIDS in 1996 (CDC, September 1997), this decline is not consistent across all populations. A follow-up report in 1998 (CDC, 1998) revealed that new cases actually rose twice as fast in the older population as compared with the younger population. In the period 1991-1996, new incident cases rose 22% (from 5269 cases to 6400 cases) among persons aged 50 and older, compared to a rise of only 9% among persons 13-49 years (from 46,000 cases to 50,300 cases). The increase was particularly notable for women, and for those whose risk was from heterosexual contact and injecting drug use.

### *Transmission Routes*

Age Group Comparisons. Table 3 presents age comparisons in the distribution of exposure categories based on the cumulative AIDS caseload as of 1996. Looking at the first two columns to examine differences across the

---

<sup>1</sup> Note that 1996 data are used here because the 1997 Public Use Data set

younger and older age groups, we see that the predominance of sexual routes as the main pathway of infection. Similar percentages of men in both categories are infected by sex with other men (49.4% for the 13-49 age group and 47.9% for the 50 plus). A few notable differences do emerge. A higher proportion of older cases are more likely to be infected through heterosexual contact (11.4% vs. 8.7%), while injecting drug use is a more common route for the younger age group (26.4% vs. 16.7%). The percentage of older persons who are infected because of receiving tainted blood has dropped dramatically since the beginning of the epidemic. At year end 1996, only 6.2% overall of the those 50 and older were infected by receipt of transfusion, although this continues to be a much larger proportion than for the younger cases (.8%). It should be noted that older AIDS cases are much more likely than younger cases (14.5% vs. 7.3%) to have an undetermined exposure category, although the reasons for this are unclear. It could be that older persons are more unwilling to provide information which would put them into an exposure category or it could be that this information is less often obtained for older persons by medical personnel.

---

had not been released at the time of writing.

Within-age comparisons. The right hand side of Table 3 examines the distribution of exposure categories within four finer age categories for the 50 plus population. In general, the proportion of cases falling within any one exposure category are relatively similar (or change gradually) for those 50-64, as compared with those under 50 years of age. The differences, however, are most notable for the 65 year plus group. Whereas homosexual sex is still the most predominant exposure category (32.5%), nearly a quarter of the population reports infection through receipt of a transfusion (22.2%), and heterosexual contact is an especially predominant category (16.3%).

Changes in exposure categories over time. Table 4 presents data on percentages of AIDS cases by exposure category for 1986 and 1996 for cases over age 50 (age at diagnosis). Several points can be noted in this examination of exposure categories for cumulative cases over a ten year period. Sexual transmission is still the most predominate route, although there has been a decrease in homosexual transmissions and an increase in heterosexual transmissions. Injecting drug use has also increased as a proportion of the exposure routes. Receipt of transmission has dropped profoundly in the older age group. These trends mirror those occurring in younger populations.

*HIV/AIDS Knowledge, attitudes and behaviors*

Although AIDS-related knowledge is increasing for all ages, older people are still less knowledgeable than younger people. For example, those 50 and older are more likely to believe that HIV/AIDS can be contracted through casual contact. As indicated in Table 5, data from the 1994 National Health Interview Survey shows that older people are more likely than younger people to believe HIV/AIDS can be gotten from being coughed on, sharing food utensils or using public toilets. Older people are also less likely than younger people to feel that they "know a lot about AIDS" or to know someone who has AIDS.

The available national data also suggest that the majority of older people in the general population do not engage in AIDS-related risk behaviors. In the early 1990s, the National AIDS Behavior Surveys (NAMS) estimated that only about 10% of older people had at least one risk factor for HIV infection such as having multiple sex partners, having a sexual partner with known behavioral risk, or having a blood transfusion between 1979 and 1985. (Stall and Catania, 1994). It may seem reasonable then that most older people do not see themselves at risk. National survey data from the 1995 Behavioral Risk Factor Surveillance

System conducted by the CDC (Mack and Bland, under review)) confirm that less than 5 per cent of adults aged 50-64 reported that their chances of getting AIDS as high or medium. Although differences were significant, the majority of younger persons also reported low risks (only 7.7 % reported their chance as high or medium).

However, the NABS study (Stall and Catania, 1994) also revealed that even when classified as "at risk", older people were unlikely to engage in AIDS-prevention behaviors. In the early 1990s, people 50 and older with a known behavioral risk for HIV infection were one sixth as likely to report using condoms during sex and one fifth as likely to have been tested for HIV than were a comparable "at risk" group in their twenties. This data is consistent with data from the 1995 BRFSS survey which shows that adults aged 50-64 were significantly less likely to ever have been tested than younger adults (23.8 % vs. 44.1%) and also less likely to have changed their behavior in last 12 months (6.9% vs. 18.3%).

While there have been modest improvements in preventive measures in heterosexuals 50 years and older with known risk factors, there is still much room for improvement. In the period from 1990-1991 to 1995-1996, testing for AIDS increased from 3% to 32%, and those

reporting they always using condoms also increased from 3% to 18% (NABS, 1997).

### *Toward the Future*

While there has been a general decrease in the numbers of new AIDS cases, it is likely that the numbers of persons 50 years and older with HIV/AIDS will continue to increase in the future. With rates of heterosexual transmission increasing, especially among the older segment of the AIDS caseload, older women are vulnerable on two fronts. Due to biological changes with aging, they are more likely than younger adult women to be infected if exposed to the HIV virus (Riley et al., 1989). While the data show that there is room for improvement in risky behaviors for persons of all ages, middle-aged and older women face a potential social disadvantage since they may be less well prepared than younger women to identify and alter risky behaviors in new social relationships (AARP, 1994). The lack of awareness is not only on the part of older people who may assume that their symptoms are due to aging-related illnesses rather than AIDS-related syndromes. Health care providers also less likely to attribute signs and symptoms presented in older people to HIV/AIDS (El-Sadr and Gettler, 1995). There is anecdotal evidence suggesting that the use

and effectiveness of aggressive treatments in older populations is questioned by patient and doctor alike, thus resulting in less than optimal care for older persons with HIV/AIDS.

In the future, the older cohort of AIDS will most likely be composed of two distinct populations: 1) those who are infected in later life, and 2) those who are infected when younger adults, but who, with better treatments, will live past fifty. As women baby boomers turn fifty, it is likely that they will engage in more risky sexual and drug-related behaviors than what is occurring in the current older population (Levy, 1998; Yates, Stellato, Johannes, and Avis, forthcoming, 1999), although the effectiveness of prevention efforts targeted to younger adults may carry over into middle-aged. Prevention efforts directed at older people and their caregivers remains, however, a critical step in increasing AIDS-related knowledge in those 50 and older, changing risky behaviors, and getting older infected people diagnosed sooner and into the most effective treatment programs. Prevention\care strategies should be sensitive to, and potentially tailored to, each of the major risk groups (e.g., older gay men, older women, and older IV drug users).

Additional research studies are needed to identify those older people at risk and to develop intervention strategies for reducing such risks and enhancing the quality of life in the middle and later years. In some cases this will entail adding an aging component to ongoing studies and databases. In other cases, it will necessitate specific studies of HIV/AIDS risks and interventions in older populations. Future research efforts should give emphasis to the variations within the older population both in terms of age and functional differences within the 50 and older population, as well as differences in risks, consequences, or treatment effectiveness due to gender or minority status. The challenge of the third decade of the HIV/AIDS epidemic is to attend to previously neglected populations at risk, and to examine the applicability of research and practice to new populations and settings.

## References

- Adler, W.H. and J.E. Nagel. 1994. "Acquired Immunodeficiency Syndrome in the Elderly, *Drugs and Aging*, 4(5): 410-416.
- American Association of Retired Persons. 1994. *Midlife and Older Women and HIV/AIDS: Report on the Seminar*.
- Brown, D.R. and A. Sankar. 1998. "HIV/AIDS and Aging Minority Populations." *Research on Aging*
- Centers for Disease Control and Prevention. *HIV/AIDS Surveillance Report*, 1996; 8(2).
- Centers for Disease Control and Prevention. *HIV/AIDS Surveillance Report*, 1997; 9(2).
- Centers for Disease Control and Prevention. 1997 "Update: Trends in AIDS Incidence, Deaths, and Prevalence—United States, 1996." *Morbidity and Mortality Weekly Report*; 46(8), 165-173.
- Centers for Disease Control and Prevention. 1998 "AIDS Among Persons Aged >50 Years—United States, 1991—*Morbidity and Mortality Weekly Report*; 47(2), 21-27.
- El-Sadr, W. and J. Gettler. 1995. "Unrecognized Human Immunodeficiency Virus Infection in the Elderly." *Arch Intern Med* 155: 184-186.
- Ferro, S. and I. Alit. 1992. "HIV Infection in Patients Over 55 Years of Age." *Journal of Acquired Immune Deficiency Syndromes*, 5: 318-353.
- Gluck, M. and E. Rosenthal. 1996. Office of Technology Assessment Report: The Effectiveness of AIDS Prevention Efforts, *The Effectiveness of AIDS Prevention Efforts - HIV Prevention: State of the Science*, Office of Technology Assessment, Washington D.C., pp. 1-39.
- Keitz, S.A., L.A. Bastian, C.L. Bennett, E.Z. Oddone, J.A. Dehovitz, R.A. Weinstein. 1996. "AIDS-related Pneumocystis Carinii Pneumonia in Older Patients." *Journal of General Internal Medicine* 11: 591-596.

- Mack, K. and Bland, S. (under review). "HIV Testing Behaviors and Attitudes Regarding HIV/AIDS of Adults Aged 50-64". Centers for Disease Control and Prevention.
- National Institute of Aging. 1997. *"AIDS and Aging Research: Current Research Activities and Priorities in the Behavioral and Social Sciences."* Administrative Document.
- National Institute of Health. Office of Aids Research. 1998 *National Institutes of Health Fiscal Year 2000: Plan for HIV-Related Research.*
- Nokes, K., ed. 1996. *HIV and the Older Adult.* Washington D.C.: Taylor and Francis.
- National AIDS Behavioral Survey. 1997, *National Sexual Health Survey*; Provisional Data provided by Catania, J., Personal Communication.
- Riley, M., M. Ory, and D. Zablotsky. 1989. *AIDS in an Aging Society,* New York: Springer.
- Skiest, D.J. and P. Keiser. (1997). "Human Immunodeficiency Virus Infection in Patients Older than 50 Years." *Archival Family Medicine* 6: 289-294.
- Skiest, D.J., E. Rubinstein, N. Carley, L. Gioiella, and R. Lyons. 1996. "The Importance of Comorbidity in HIV-infected patients over 55: A retrospective case-control study." *American Journal of Medicine* 101: 605-611.
- Stall, R. and J. Catania. 1994. "AIDS Risk Behaviors Among Late Middle-aged and Elderly Americans. The National AIDS Behavioral Surveys." *Archives of Internal Medicine* 154: 57-63.
- Strombeck, R. 1998. "Educational Strategies and Interventions Targeting Adults Over 50 for HIV/AIDS Prevention." *Research on Aging*
- UCSF 1997. "What are HIV prevention Needs of Adults Over 50?", Center for AIDS Prevention Studies, AIDS Research Institute

- Yates, M.E., R.K. Stellato, C.B.Johannes, and N.E. Avis.  
Forthcoming, 1999. "The Importance of AIDS-Related  
Knowledge for Mid-Life and Older Women.", *AIDS Care*.
- Whipple, B. and K.W. Scura.1996. "The Overlooked Epidemic:  
HIV in Older Adults." *American Journal of Nursing* 96:  
22-28.
- Zablotsky, D. 1998. "Older Women and AIDS." *Research on  
Aging*.

**Table 1.**  
**Cumulative AIDS Cases Reported, Year-end 1997, by Age at Diagnosis**

Age at Diagnosis	Total	Percent	Percent Distribution (for those over 50)
<5	6,343	1.0	
5-12	1,743	0.0	
13-19	3,130	0.0	
20-24	22,953	3.6	
25-29	88,415	13.8	
30-34	146,712	22.9	
35-39	143,381	22.4	
40-44	103,660	16.2	
45-49	58,516	9.1	
50-54	30,789	4.8	46.5
55-59	17,251	2.7	26.0
60-64	9,662	1.5	14.6
>65	8,530	1.3	12.9
Total*	641,086		

\*Total includes 1 person whose age at diagnosis is unknown.

Source, Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 1997; 9(2).

**Table 2.**  
**Number of Persons Living with AIDS, Year-end 1996 by Age\***

<b>Age Group</b>	<b>Estimated Actual Age, Year-end 1996, Number of Cases</b>	<b>Percent</b>
1-12	2,728	1.1
13-19	1,725	.7
20-24	3,524	1.5
25-29	16,731	7.0
30-34	42,056	17.7
35-39	55,170	23.2
40-44	49,446	20.8
45-49	33,229	13.9
50-54	17,081	7.2
55-59	8,455	3.5
60-64	4,283	1.8
65+	3,782	1.6
Total	240,206	100.0

Source of data: AIDS Public Information Data Set, CDC 1996. Estimates of persons living with AIDS were derived by subtracting the cases with a reported death certificate from the estimated cumulative number of persons with AIDS and as such, should be interpreted with caution given reporting delays and incomplete reporting of deaths.

**Table 3.**  
**Cumulative Percentage of AIDS Cases 1996,**  
**According to Exposure Category and Age at Diagnosis**

<b>Exposure Category</b>	<b>13-49</b>	<b>50+</b>	<b>50-54</b>	<b>55-59</b>	<b>60-64</b>	<b>65+</b>
Men who have sex with men	49.4	47.9	51.7	49.6	46.1	32.5
Injecting drug use	26.4	16.7	21.1	16.2	11.9	7.5
Men who have sex with men and injecting drug use	6.8	2.5	3.4	2.4	1.6	.8
Hemophilia/coagulation disorder	.7	.8	.6	.7	1.1	1.6
Heterosexual contact	8.7	11.4	9.7	11.4	12.8	16.3
Receipt of transfusion	.8	6.2	2.3	3.9	8.4	22.2
Other/undetermined	7.3	14.5	11.3	15.8	18.1	19.3
Total Number of Cases	514,376	59,424	27,514	15,512	8,716	7,682

\*Data adjusted to account for reporting delays.

Source of data: AIDS Public Information Data Set, CDC 1996.

**Table 4.**  
**Cumulative Percentage of AIDS Cases for Older Adults, 1986 & 1996,**  
**According to Exposure Category and Age at Diagnosis**

<b>Exposure Category</b>	<b>1986 50+</b>	<b>1996 50+</b>
Men who have sex with men	64.6	47.9
Injecting drug use	8.1	16.7
Men who have sex with men and injecting drug use	2.6	2.5
Hemophilia/coagulation disorder	1.9	.8
Heterosexual contact	2.4	11.4
Receipt of transfusion	15.2	6.2
Other/undetermined	5.3	14.5
Total Number of Cases	4,136	59,424

\*Percentages adjusted to account for reporting delays.

Source of data: AIDS Public Information Data Set, CDC 1996.

**Table 5.**  
**Prevalence of Beliefs and Knowledge About HIV/AIDS, by Age Group, 1994**

	<b>Age of Respondent</b>	
	<b>18-49</b>	<b>50+</b>
<b>Percentage Reporting it is “likely” that HIV/AIDS can be gotten from:</b>		
Being coughed on	21	34
Sharing food utensils	20	32
Using public toilets	7	13
<b>AIDS Knowledge</b>		
Knows a lot about AIDS	40	23
Knows someone who has AIDS	29	20

Source: 1994 National Health Interview Survey. Percentages weighted by AIDS final weight.